

## Factors affecting defaulting from services among people living with HIV at two treatment centers in Western province, Sri Lanka

Dr PADMP Perera<sup>1</sup>, Dr WS Pannala<sup>1</sup>, Dr KAM Ariyaratne<sup>2</sup>, Dr Jayadarie Ranathunga<sup>3</sup>, Dr PGW Hemamala<sup>4</sup>

### Abstract

**Introduction:** Failure to retention in care or lost to follow up (LFU) is a challenge in the lifelong HIV care continuum as it results in adverse clinical and preventive outcomes. This study explores social and clinical factors that contribute to loss to follow up among PLHIV.

**Objective:** to describe factors affecting loss to follow up among PLHIV at two high-burden, treatment centers in the Western Province, Sri Lanka.

**Method:** A comparative cross-sectional study was conducted in STD clinics Colombo and Ragama. LFU was defined as failure to attend a given appointment for three months. PLHIV who were registered from February 2016 to February 2019 and were LFU at least once were chosen as the study population. PLHIV who continuously retained in care, in the same time period, were chosen for comparison by systematic sampling. Socio demographic, clinical and LFU data were collected as secondary data, using a pre tested checklist and analyzed by SPSS.

**Results:** Income levels, proportions of key populations and vulnerable populations, WHO stage and performance scale at registration were similar among both groups.

Shorter distance to ART center, unknown serostatus of the regular partner, non-disclosure and absence of a treatment supporter were significantly associated with loss to follow up in this study population.

Disclosure status and the presence of a treatment supporter was significantly associated with success of defaulter tracing.

**Conclusion:** It is important to consider non-disclosure, absence of a treatment supporter and partner's serostatus when addressing loss to follow up among PLHIV.

**Key words:** Defaulted PLHIV, HIV care, Loss to follow up

**Authors:** <sup>1</sup>Dr PADMP Perera (MBBS, PgD Ven, MD), Senior registrar in Venereologist, National STD/AIDS Control programme (NSACP), Sri Lanka, <sup>1</sup>Dr WS Pannala (MBBS, PgD Ven, MD), Senior Registrar in Venereology, NSACP, <sup>2</sup>Dr KAM Ariyaratne (MBBS, MSc, MD), Consultant Venereologist, NSACP, <sup>3</sup>Dr Jayadarie Ranatunga (MBBS, DCH, PgD Ven, MD), Consultant Venereologist, STD clinic- Ragama, <sup>4</sup>Dr PGW Hemamala (MBBS, PgD Ven), Diploma Trainee in Venereology, NSACP

**Corresponding author:** <sup>1</sup>Dr PADMP Perera, Email; [piyumipp@gmail.com](mailto:piyumipp@gmail.com);

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## Full Article

### Introduction

Sri Lanka is a country with a low HIV prevalence which was maintained for the past decade or so. However, as the HIV testing services have been scaled up and rolled out island wide, the number detected is rising stably. At the end of the 4th quarter of 2018, a cumulative number of 3192 People living with HIV (PLHIV) were identified.<sup>1</sup> According to the policy decision taken in 2016, the “test and treat” concept is adhered in the HIV services in Sri Lanka, resulting in a considerable number of PLHIV being on anti-retroviral treatment (ART). The total number receiving HIV care services by the end of 2017 was 1355 and of them 1299 were on ART.<sup>2</sup> This number has been increasing during the year 2018 resulting in a significant patient load for the ART centers.

One of the main problems faced by the HIV care providers is retention in care by the PLHIV. Lost to follow up or defaulting is identified as a long term challenge in this complicated public health setting. A PLHIV is categorized as a defaulter when he/she does not attend the clinic for 3 months from the given date of appointment.<sup>3</sup> This issue is a major factor affecting the country objectives for HIV care.

Patients who discontinue treatment are at high risk of illness and death because of AIDS-related conditions.<sup>4</sup> Furthermore, ART is also used as treatment as prevention. The recent evidence showing undetected = untransmissible is also very important to control the epidemic and to reach county targets. Defaulting of the PLHIV will hinder all these achievements and will lead to increased morbidity and mortality.

At present, the HIV treatment policy has changed to “treat all” resulting in more PLHIV being on treatment. Furthermore, several clinics have been identified as high burden centers in the Western province. The central STD clinic Colombo is the center which caters for the highest number of PLHIV in the country. Over 20,000 patients seeking services for sexual health related problems accessed Colombo clinic in 2018.<sup>1</sup> Colombo clinic is the

one with the highest number of registered PLHIV in the country as well, followed by STD clinic Ragama, with the second highest PLHIV numbers in the western province. It has been observed that the defaulter rates among these centers are significant.

The records of the PLHIV are being maintained by the STD clinic staff meticulously and a register for defaulter tracing is also maintained by the clinics to follow up the PLHIV who defaulted and to record what actions have been taken in view of linking them to care services. The public health staff allocated to the STD clinics, i.e. PHI and PHNS are responsible for the maintenance of this register. Furthermore, the PHIs maintain an excel data base with all the individual data and this is being updated weekly for strategic information purposes.

Therefore, it is important to generate new knowledge in respect to the current situation to identify the factors and challenges and address them accordingly.

Thus, the objective of this study was, to describe factors affecting defaulting from services among PLHIV in two treatment centers in the western province, Sri Lanka.

### Methods

This is a comparative cross sectional study conducted in the Central HIV clinic Colombo and STD clinic Ragama. The study population was all registered PLHIV excluding those who are less than 18 years from February 2016 to February 2019 in these 2 study sites, as the “test and treat” policy was established from February 2016. Two groups were identified as defaulters: a person who has not attended the clinic at least once for 3 months from the given date during 2016/01/01 – 2018/12/31 and retained PLHIV: Individuals who had been on ART for at least 6 months and are rated as excellent adherers by the providers registered between 2016/01/01 – 2018/12/31. For each defaulter, 2 retained PLHIV who were enrolled in the same month were selected. To increase the power of the study, a higher number of PLHIV who are retained were chosen. When selecting them, the closest date of enrolment as the defaulter was also considered. Both the

defaulter and retained PLHIV were assessed using the same data collection method.

Secondary data were collected using HIV clinic records. The patient files were used to collect data by the researchers after gaining permission from the authorities. If the records of the defaulters who had passed away were available, those data were included in the study as well. Data on the defaulter tracing mechanism and the actions taken were collected using individual files as well as the Defaulter tracing register and the cross sectional excel data base. Data were analyzed by SPSS. Ethical approval was obtained from the Ethical Review Committee of the National Hospital of Sri Lanka.

## Results

### Socio demographic characteristics

A total of 37 PLHIV who were defaulted during the above study period and a comparison group of 74 PLHIV who retained in care were identified. The mean age of the defaulted PLHIV was 38.8 years (SD-9.349) and retained PLHIV were 41.1 years (SD-11.605). Majority of both groups were in the 25-49 years age category, Sinhalese, males and were married. More than 70% of both groups were employed as well. Higher proportion of non defaulted PLHIV had G.C.E. O/L or higher education compared to the defaulted PLHIV and this was statistically significant. The mean distance to treatment center between these two groups was different significantly as well.

Table 1: Socio demographic characteristics of defaulted and the non-defaulted groups

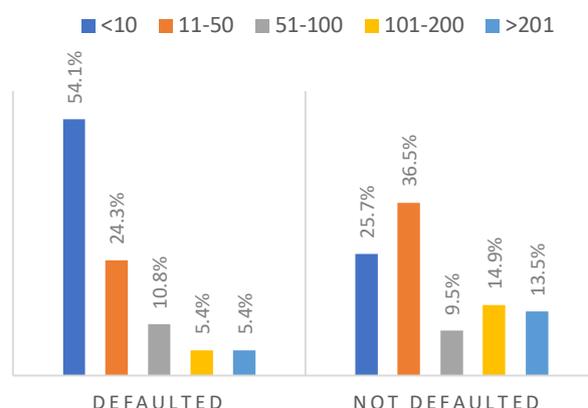
Characteristic	Defaulted PLHIV (n=37)	Not defaulted PLHIV (n=74)	Significance
Age			
Mean	38.8 years	41.1 years	p = 0.30
Range	24 – 57 years	21 – 68 years	
Age categories (%)			
18-24 yrs	2.7	5.4	p = 0.74
25-49 yrs	78.4	73	
>50 yrs	18.9	21.6	

Sex (%)			
Male	73	81.1	p= 0.33
Female	27	18.9	
Nationality (%)			
Sinhala	78.4	78.4	p=0.26
Tamil	13.5	13.5	
Muslim	2.7	6.8	
Burgher	0	1.4	
Foreign	5.4	0	
Marital status (%)			
Single	24.3	36.5	p=0.055
Married	45.9	52.7	
Divorced	2.7	1.4	
Separated	24.3	5.4	
Widowed	2.7	4.1	
Educational level (%)			
No schooling	8.1	5.4	p= 0.02*
Grd 1-5	5.4	1.4	
Grd 6-10	37.8	21.6	
O/L	24.3	36.5	
A/L	16.2	18.9	
Dip/ Degree	8.1	16.2	
Distance to treatment center in km			
Mean	37.4 km	73.45 km	p=0.02
Range	3 – 266 km	1 – 311 km	
Number of children (%)			
0	51.4	45.9	p =0.57
1	21.6	16.2	
2	18.9	25.7	
3	8.1	5.4	
4	0	5.4	
5	0	1.4	
Employment status (%)			
Employed	86.5	73	p = 0.14
Unemployed	13.5	27	
Income categories in SLR (%)			
Less than 10,000	2.7	2.7	p = 0.21
10,001 – 50,000	54.1	33.8	
50,001 – 100,000	10.8	14.9	
>100,001	2.7	2.7	
Dependent	2.7	0	
Not recorded	27	45.9	

\* (Educational level O/L and above)

It was interesting to note that more than 50% of the defaulted group lived less than 10 kms from the treatment center and this was statistically significant . (p=0.037, Figure 1)

Figure 1: Distance of residence to treatment center in Kilometres



Further socio demographic data analysis showed that there were no statistically significant differences in the proportion of key and vulnerable populations, prevalence of substance abuse, history of imprisonment and whether linked to a Non-governmental organization or not, between the defaulted and the non-defaulted groups.

Table 2: Socio demographic characteristics of defaulted and the non-defaulted groups (continued)

Characteristic	Defaulted PLHIV (n=37)	Not defaulted PLHIV (n=74)	Significance testing
<b>Belongs to a key population (%)</b>			
Yes	37.8	35	p=0.0782
No	62.2	65	
<b>Belongs to a vulnerable population (%)</b>			
Yes	54.1	58	p=0.6844
No	45.9	42	
<b>Substance use (%)</b>			
Yes	59.5	50	p=0.3464
No	40.5	50	
<b>History of imprisonment (%)</b>			
Yes	13.5	6.8	p=0.3025
No	86.5	90.5	
Not recorded	0	2.7	
<b>Link to NGO (%)</b>			
Yes	2.7	10.8	p =0.272
No	83.8	89.2	
Not recorded	13.5	0	

### Clinical characteristics

Among the clinical characteristics, unawareness of partner's serostatus, non-disclosure of one's own serostatus and absence of a treatment supporter were significantly associated with defaulting, whereas presence of a comorbidity was significantly associated with retaining in care in this study population.

Table 3: Clinical characteristics of the defaulted and the non-defaulted groups

Characteristic	Defaulted PLHIV (n=37)	Not defaulted PLHIV (n=74)	Significance testing
<b>WHO stage at registration (%)</b>			
1	70.3	74.3	p=0.776
2	8.1	9.5	
3	10.8	5.4	
4	10.8	10.8	
<b>Performance scale at registration (%)</b>			
A	91.9	95.9	p=0.343
B	8.1	2.7	
C	0	1.4	
<b>Presence of comorbidities (%)</b>			
Yes	29.7	54.1	p=0.015
No	70.3	45.9	
<b>Awareness of partner's serostatus (%)</b>			
Yes	27	50	p=0.0209
No	73	50	
<b>Disclosed (%)</b>			
Yes	40.5	63.5	p=0.0405
No	56.8	36.5	
Not recorded	2.7	0	
<b>Presence of a treatment supporter (%)</b>			
Yes	29.7	54.1	p=0.0393
No	64.9	45.9	
Not recorded	5.4	0	
<b>ART regimen (%)</b>			
Preferred	82.6	86.5	p=0.735
Alternative	17.4	13.5	
<b>Side effects recorded (%)</b>			
Yes	13.1	33.8	p=0.067
No	86.9	66.2	
<b>ART regimen changed (%)</b>			
Yes	17.4	25.7	p=0.577
No	82.6	74.3	

To account for the confounding factors, a logistic regression was conducted, and the odds ratios of the presence of a comorbidity

and education level were found to be significant. Though not significant, awareness of partner's serostatus, disclosure of patient's serostatus and the presence of a treatment supporter were protective factors from defaulting from care.

Less than 10km distance from residence to treatment center was shown to be a risk factor for defaulting.

Table 4: logistic regression analysis of the socio demographic and the clinical characteristics and defaulting from services (*Chi square -23.4121, df-6, p-0.0007*)

Variable	Coefficient	Standard error	P value	Odds Ratio	95% Confidence interval
Distance	1.0908	0.5591	0.0511	2.97	(0.9950,8.9050)
Partner serostatus	-0.4662	0.5702	0.4136	0.63	(0.2052,1.9182)
Disclosure	-0.7205	0.7258	0.3209	0.49	(0.1173,2.0179)
Treatment supporter	-0.1636	0.6875	0.8119	0.85	(0.2207,3.2669)
Comorbidities	-1.3036	0.5006	0.0092	0.27	(0.1018,0.7244)
Educational status	-0.9127	0.4581	0.0463	0.40	(0.1639,0.9853)

Table 5: Factors associated with the success of defaulter tracing

	Characteristic	Tracing successful (n=14)	Tracing not successful (n=23)	Significance testing
Disclosure	Yes	10	5	p=0.0061
	No	4	17	
Treatment supporter	Present	6	3	p=0.0115
	Absent	8	18	

Table 6: Logistic regression analysis of socio demographic and clinical characteristics and the success of defaulter tracing mechanism (*Chi square-10.5478, df-2, p-0.0051*)

Variable	Coefficient	Standard error	P value	Odds ratio	95% confidence interval
Disclosure	1.5077	0.9564	0.1149	4.52	(0.6926,29.4369)
Treatment supporter	1.2182	1.0175	0.2312	3.38	(0.4602,24.8413)

### Results of Defaulter tracing actions

Out of the 37 defaulters, only 1 had not undergone defaulter tracing.

50% of defaulters were traced through telephone calls, the rest via more than one method according to their preference (e.g. – call + letter + home visits)

Only 37.8% (n=14) returned to care and hence defaulter tracing successful

Analysis was carried out to find out any significant associations with the socio demographic and clinical characteristics and the success of defaulter tracing in the defaulter group. Positive disclosure status and the presence of a treatment supporter were significantly associated with the success of defaulter tracing.

Furthermore, logistic regression analysis showed that there was no statistically significant difference for these factors. However, the odds ratio for both characteristics are more than 1 suggesting that this could be clinically significant.

### Discussion

Loss to follow up or defaulting is a significant problem encountered at centers which provide HIV care services, and this will hinder the HIV care pathway and lead to a grave clinical as well as a public health problem. Therefore, it is always important to look into factors affecting loss to follow up, so the services can amend their methods in approaching this problem and tackle it in an effective manner.

In 2015, a study was conducted to look into reasons for loss to follow up at the Central Clinic – Colombo.<sup>5</sup> The results of that study revealed that the main reason for LFU in males was alcohol and substance abuse (48.3%). In our study, the prevalence of substance use was almost 60% for the defaulters and 50% for the non-defaulted PLHIV. However, there was no statistically significant difference between these two groups suggesting that even though this is prevalent, it may not be a deciding factor for defaulting from services. It should also be noted that our study did not disaggregate data according to the sex of the participants.

In the same study done previously, imprisonment was identified as another reason for LFU among males with a prevalence of 7.8%.<sup>5</sup> In our study 13.5% of the defaulted PLHIV and 6.8% of the non-defaulted PLHIV has had a history of imprisonment. This finding was not statistically significant between the two groups. Furthermore, the previous study showed a prevalence of 7.8% of male participants experiencing side effects for antiretroviral treatment and was identified as a reason for LFU.<sup>5</sup> In our study, which was conducted in the era of “treat all”, the study populations had higher prevalence of side effects: defaulted PLHIV – 13.5%, non-defaulted PLHIV-33.8%, but there was no statistically significant difference between the compared groups in experiencing side effects, suggesting that this is not affecting retaining in care service.

Among the females in the study done in 2015, lack of partner support (30.7%) was a reason for defaulting.<sup>5</sup> In our study 64.9% of defaulted PLHIV did not have a treatment supporter and this was statistically significant as well.

In Ethiopia, a study was conducted with ART users at Jimma University Specialized Hospital (JUSH) to find out the prevalence of and factors associated with defaulting from antiretroviral treatment (ART) in Jimma, Ethiopia. In the logistic-regression model, 5 factors were found to be independently associated with ART defaulting: taking hard drugs (cocaine, cannabis and IV drugs); drinking alcohol most of the time; being bedridden; living outside Jimma town; and having an HIV negative

partner (or of unknown HIV status).<sup>6</sup> In our study we found that defaulting from services was significantly associated with absence of a comorbidity and having a lower educational level in the logistic regression model.

Another study conducted in Nambia in 2008/2009 revealed that having to travel a long distance to the ART clinic will result in defaulting.<sup>7</sup> However, in our study, it was interesting to note that defaulting was significantly associated with living less than 10km from the treatment center.

## Conclusion

This study opened up new areas to think of when we are developing mechanisms to minimize loss to follow up. When addressing PLHIV during their HIV care, attention should be given to encourage them to disclose their serostatus and for partner testing. Identifying and having a treatment supporter is also an important area to discuss as this is significantly associated with less defaulting from services and with the success of defaulter tracing mechanisms. May be due to the small sample size, the logistic regression model did not show significance to some of the factors, but the odds ratios suggested that these factors have clinical significance. Furthermore, it is important to study the fact that defaulting is significant if the PLHIV is living less than 10km distance from the treatment center. It is important to find out whether this is because they have provided a temporary address or whether it is due to stigma associated with being identified by familiar people. Therefore, during the counselling sessions with PLHIV, it would be worthwhile to discuss these issues in depth and in a sensitive manner as it will help in minimizing defaulting from HIV care services.

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